Development of CAN-EMPOWER

The CANcer EMotional and Psychological Oncology WEll-being pRoject

Prof Lynn Calman, Dr David Wright, Dr Dan Aze

29th October, 2024

With thanks to

- **Development group;** Michael Baliousis, Ken Banks, Dany Bell, Joanna Calder, Fiona Campbell, June Davis, Claire foster, Marcia Hudson, Chloe Grimmett, Angela McCullagh Andrew Merwood, Sebastien Pollet, Janice Preston, Jackie Rafferty, Alison Richardson, Richard Stephens, Tracy Williams
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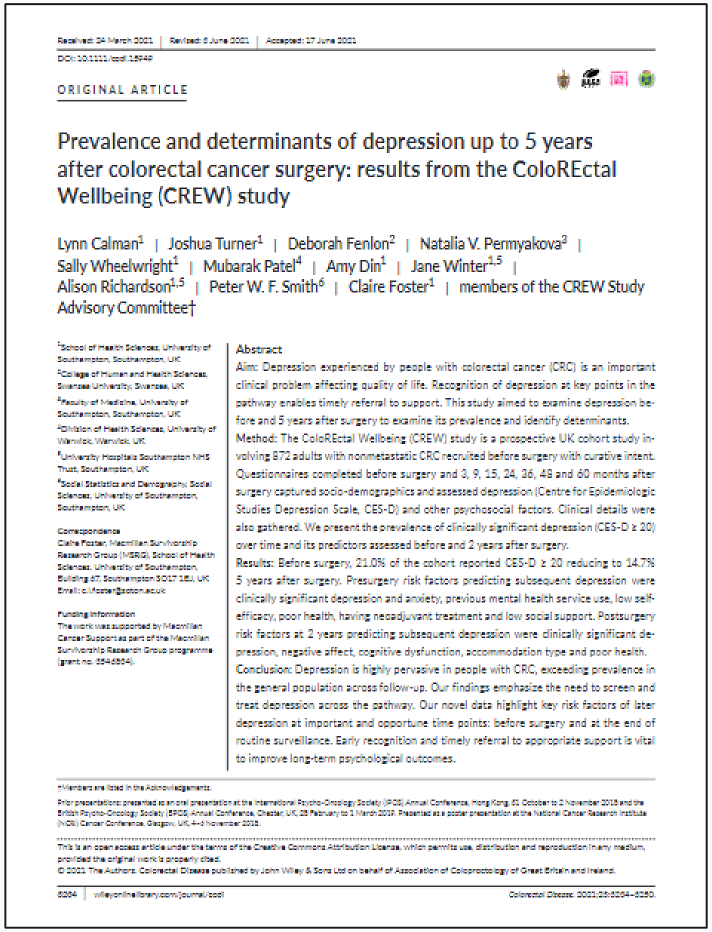
- All of the people who took part and shared their thoughts in our workshops and interviews
- All of the support groups and charities that helped advertise our project

Emotional wellbeing in people with a cancer diagnosis

- Psychosocial distress is common in cancer patients and survivors and encompasses a broad range of concerns and psychological symptom
  - effects 30-60% of populations (different measures)
  - Differs by gender and tumour groups
  - Depression and anxiety also reported to be at higher levels than the general population (Niedzwiedz *et al* 2019)



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ORIGINAL ARTICLE

Prevalence and determinants of depression up to 5 years after colorectal cancer surgery: results from the ColoREctal Wellbeing (CREW) study

Lynn Calman[1] | Joshua Turner[1] | Deborah Fenlon[2] | Natalia V. Permyakova[3] | Sally Wheelwright[1] | Mubarak Patel[4] | Amy Din[1] | Jane Winter[1,5] | Alison Richardson[1,5] | Peter W. F. Smith[6] | Claire Foster[1] | members of the CREW Study Advisory Committee†

[1]School of Health Sciences, University of Southampton, Southampton, UK
[2]College of Human and Health Sciences, Swansea University, Swansea, UK
[3]Faculty of Medicine, University of Southampton, Southampton, UK
[4]Division of Health Sciences, University of Warwick, Warwick, UK
[5]University Hospitals Southampton NHS Trust, Southampton, UK
[6]Social Statistics and Demography, Social Sciences, University of Southampton, Southampton, UK

Correspondence
Claire Foster, Macmillan Survivorship Research Group (MSRG), School of Health Sciences, University of Southampton, Building 67, Southampton SO17 1BJ, UK
Email: c.l.foster@soton.ac.uk

Funding information
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Abstract

Aim: Depression experienced by people with colorectal cancer (CRC) is an important clinical problem affecting quality of life. Recognition of depression at key points in the pathway enables timely referral to support. This study aimed to examine depression before and 5 years after surgery to examine its prevalence and identify determinants.

Method: The ColoREctal Wellbeing (CREW) study is a prospective UK cohort study involving 872 adults with nonmetastatic CRC recruited before surgery with curative intent. Questionnaires completed before surgery and 3, 9, 15, 24, 36, 48 and 60 months after surgery captured socio-demographics and assessed depression (Centre for Epidemiologic Studies Depression Scale, CES-D) and other psychosocial factors. Clinical details were also gathered. We present the prevalence of clinically significant depression (CES-D ≥ 20) over time and its predictors assessed before and 2 years after surgery.

Results: Before surgery, 21.0% of the cohort reported CES-D ≥ 20 reducing to 14.7% 5 years after surgery. Presurgery risk factors predicting subsequent depression were clinically significant depression and anxiety, previous mental health service use, low self-efficacy, poor health, having neoadjuvant treatment and low social support. Postsurgery risk factors at 2 years predicting subsequent depression were clinically significant depression, negative affect, cognitive dysfunction, accommodation type and poor health.

Conclusion: Depression is highly pervasive in people with CRC, exceeding prevalence in the general population across follow-up. Our findings emphasize the need to screen and treat depression across the pathway. Our novel data highlight key risk factors of later depression at important and opportune time points: before surgery and at the end of routine surveillance. Early recognition and timely referral to appropriate support is vital to improve long-term psychological outcomes.

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†Members are listed in the Acknowledgements.

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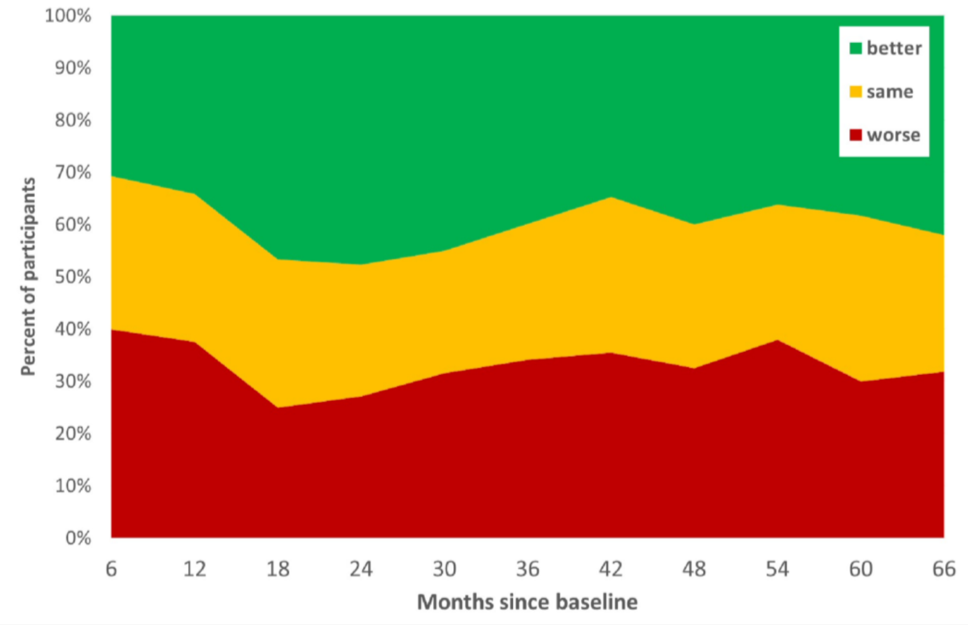
The need for psychological support

- **Psychosocial factors** as good a predictor as stage at diagnosis for long-term recovery of health and wellbeing

- **Depression** and **low self-efficacy** at diagnosis were the most consistent predictors of poor health and wellbeing outcomes



Changes in quality of life (QLACS-GSS) compared to baseline

Wheelwright et al. (2020). *Plos One*, **15** (4)

UK Policy Context

NICE Guidelines (2004)[1]

Level	HCP Group	Intervention
1	All health and social care professionals	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Psychological techniques such as problem solving
3	Trained and accredited professionals	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Specialist psychological and Psychiatric interventions such as psychotherapy, including cognitive behavioural therapy.

NHS England Comprehensive Personalised Care Model[2]

Group	Intervention	Outcome
Whole population 100%	**Universal** Shared Decision Making. Enabling choice (e.g. in maternity, elective and end of life care). Social prescribing and community connecting roles. Community capacity building.	Supporting people to stay well and building community resilience, enabling people to make informed decisions and choices when health changes.
People with long term physical + mental health conditions 30%	**Targeted** Proactive case finding and personalised care and support planning through general practice. Support to self manage by increasing patient activation through health coaching, peer support and self management.	Supporting people to build knowledge, skills and confidence and to live well with their health conditions.
People with complex needs 5%	**Specialist** Integrated Personal Commissioning, including proactive case finding; personalised care and support planning through multidisciplinary teams; personal health budgets and integrated personal budgets.	Empowering people, integrating care and reducing unplanned service use.

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[1] Improving Supportive and Palliative Care for Adults with Cancer, 2004. National Institute for Clinical Excellence

[2] https://www.england.nhs.uk/wp-content/uploads/2019/02/comprehensive-model-of-personalised-care.pdf

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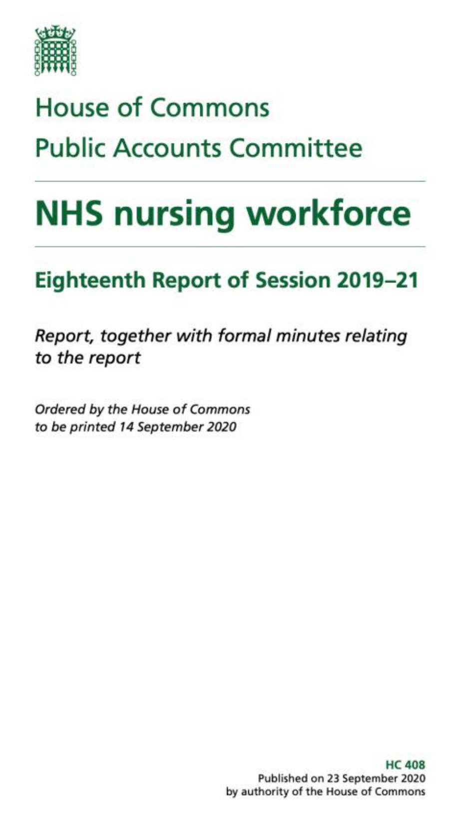
UK Practice Context



House of Commons
Public Accounts Committee

NHS nursing workforce

Eighteenth Report of Session 2019–21

Report, together with formal minutes relating to the report

Ordered by the House of Commons to be printed 14 September 2020

HC 408
Published on 23 September 2020
by authority of the House of Commons

Voices from the frontline:

Challenges facing cancer clinical nurse specialists right now

MACMILLAN CANCER SUPPORT
RIGHT THERE WITH YOU

WORKFORCE

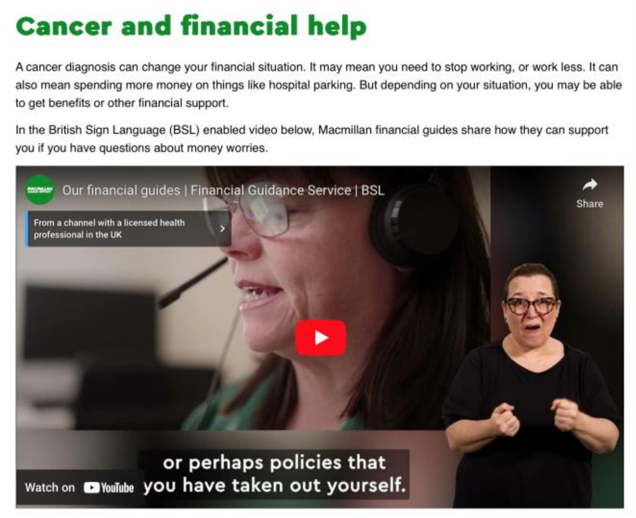
Record number of nurses leaving the NHS in England

30 SEPTEMBER, 2022 | BY ELLA DEVEREUX

Source: Shutterstock

40,000 nurses

Digital Resources



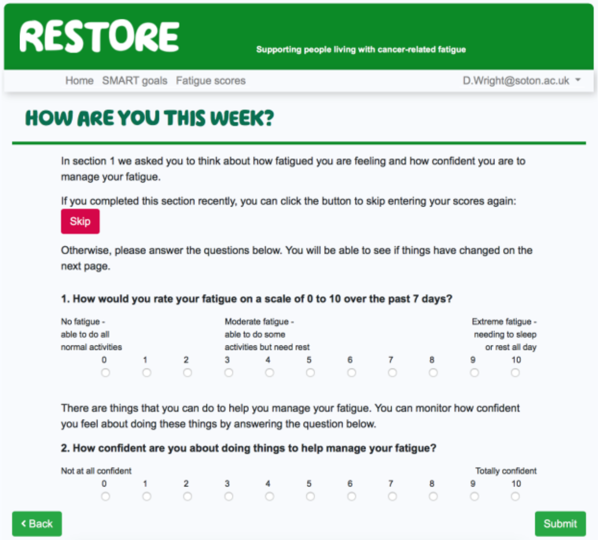
Cancer and financial help

A cancer diagnosis can change your financial situation. It may mean you need to stop working, or work less. It can also mean spending more money on things like hospital parking. But depending on your situation, you may be able to get benefits or other financial support.

In the British Sign Language (BSL) enabled video below, Macmillan financial guides share how they can support you if you have questions about money worries.

or perhaps policies that you have taken out yourself.

Sleepio



HOW ARE YOU THIS WEEK?

In section 1 we asked you to think about how fatigued you are feeling and how confident you are to manage your fatigue.

If you completed this section recently, you can click the button to skip entering your scores again:

Skip

Otherwise, please answer the questions below. You will be able to see if things have changed on the next page.

1. How would you rate your fatigue on a scale of 0 to 10 over the past 7 days?

No fatigue - able to do all normal activities
Moderate fatigue - able to do some activities but need rest
Extreme fatigue - needing to sleep or rest all day

0	1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○	○

There are things that you can do to help you manage your fatigue. You can monitor how confident you feel about doing these things by answering the question below.

2. How confident are you about doing things to help manage your fatigue?

Not at all confident
Totally confident

0	1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○	○

‹ Back
Submit

MACMILLAN CANCER SUPPORT

Aims of CAN-EMPOWER

To develop a **freely available**, **evidence-based** digital resource to **enhance confidence** (self-efficacy) to self-manage **psychological problems/well-being** for people living with and beyond cancer.

Objectives

- Identify potential **components** and **content** of the online resource.
- **Develop** and **user-test** the online resource, co-creating and refining the intervention with patients, carers and clinical experts.

Study Design

PLAN

OPTIMISE

IMPLEMENT

- Literature and Web review
- HORIZONS data analysis
- Development Group Meeting 1
- Theory of Change / Logic Model
- NGT Workshops

Intervention planning table / Guiding Principles

Development Group Meeting 2
Nov 2023

Prototype Development

Think aloud testing
Mar 2023-May 2024

Development Group Meeting 3
Apr 2024

Home Testing, Structured Evaluation, & Retrospective Interviews
July - Aug 2024

Development Group Meeting 4
Aug 2024

Final Resource ready to launch
December2024

Approach informed by the Person-Based Approach (Yardley *et al* 2015)

Iterative and evidence-based method of intervention development that has the person's experience at its heart

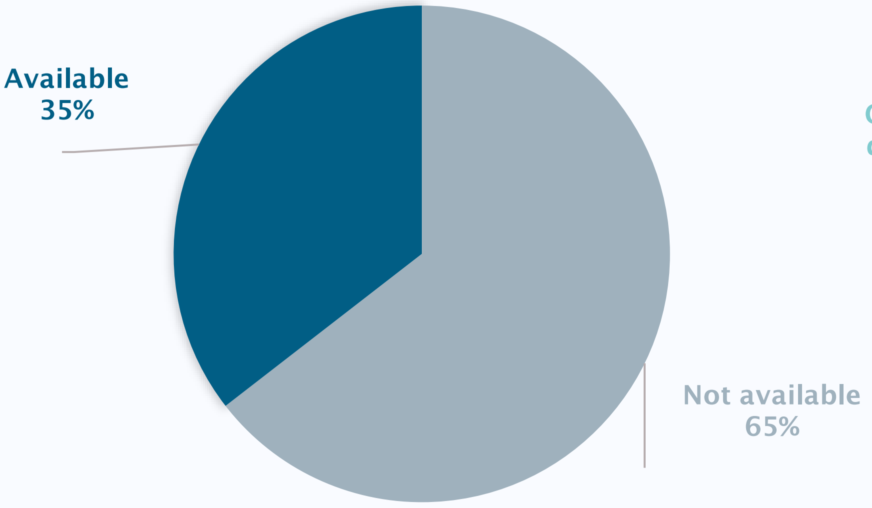
- Understand and meaningfully address the views, needs and experiences of intervention users
- Understand the context within which users are engaging with the intervention change
- Consider how theory- and evidence-based content can be delivered and communicated in the most engaging and persuasive way
- Systematically document, agree and prioritise required intervention elements and changes

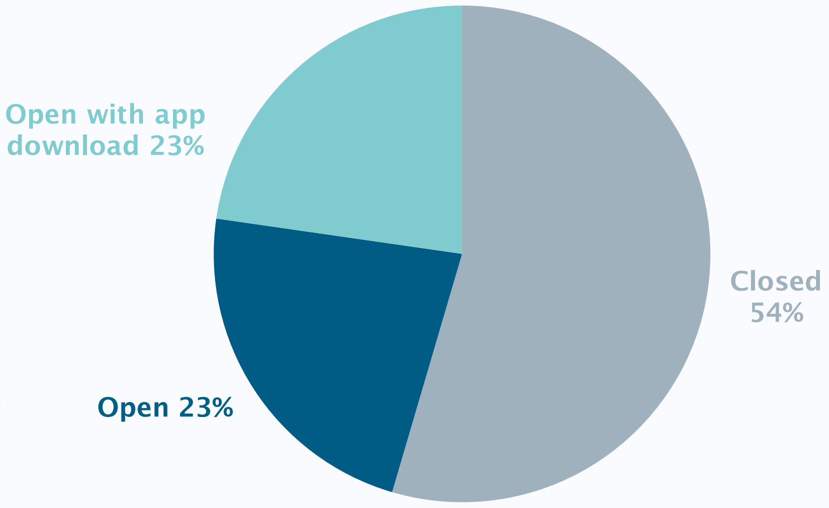
https://personbasedapproach.org/pba_diagram.html

https://personbasedapproach.org/

Literature review

- No study with equivalent intention and purpose
- 22/63 published interventions publicly available
- 17/22 published interventions are free; 10/22 are 'open'





Qualitative literature review findings

What helps?	What hinders?
• Timing • Taking control • Positive tone • Self-paced • Tailored • Flexible: device and location • Focus on mental health, not cancer • Trustworthy • Relevant • Ease of navigation • Reassuring • Evidence	• Too much information / options • Irrelevant • Feeling overwhelmed • Including advanced cancer • Not worth their time • Symptoms and side effects • Activities too long • Pressure to do too much • Evidence

HORIZONS data analysis

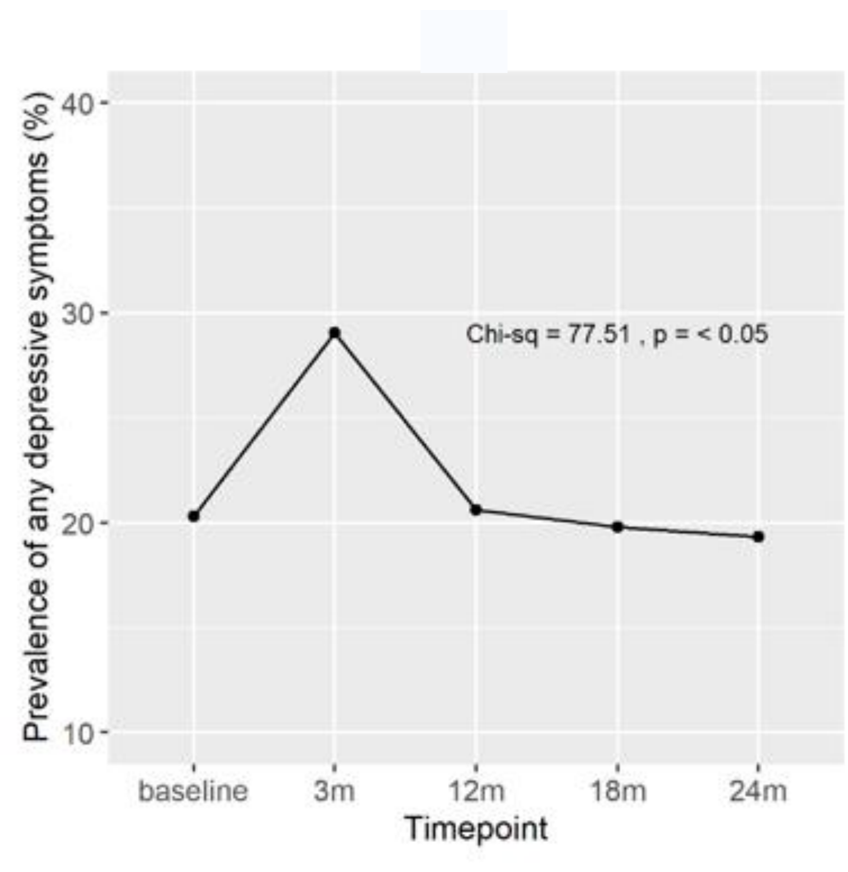
- HORIZONS longitudinal cohorts to understand recovery and wellbeing in 3442 people with breast cancer, gynaecological cancer and people with NHL
- First data collection before treatment then at 3, 12, 18, 24, 36 months later

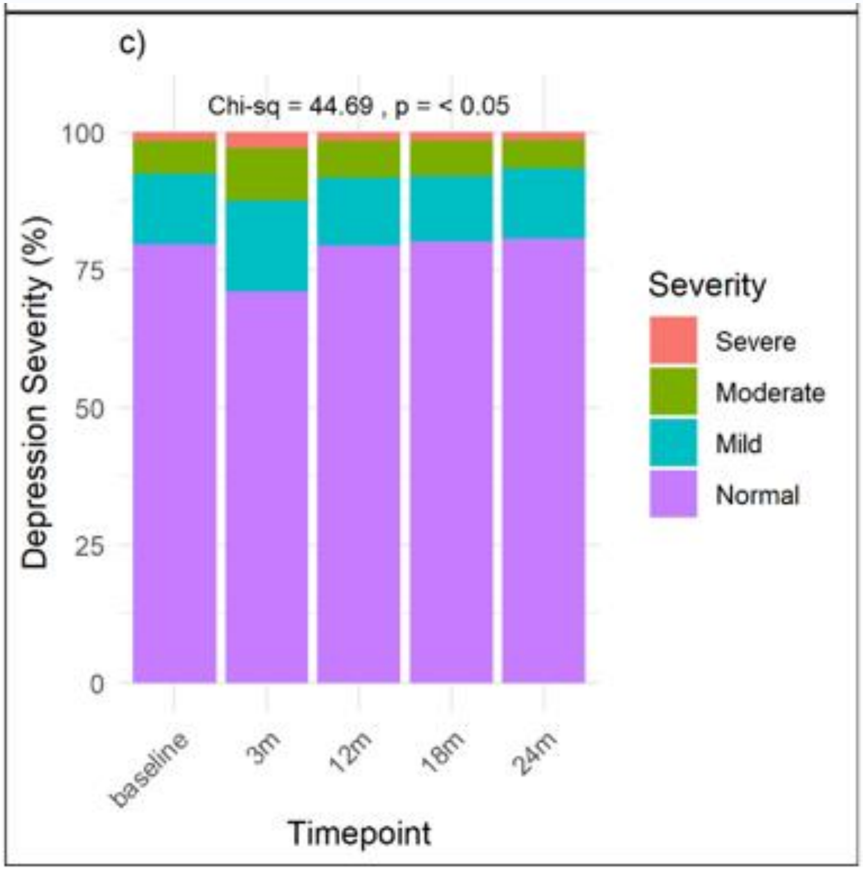
This analysis Hospital Anxiety and Depression Scale (HADS)

- 363 breast cancer patients, 182 NHL patients, 344 Gynaecological patients
- 3 months -24 months
- Prevalence of anxiety and depression mild, moderate and severe.

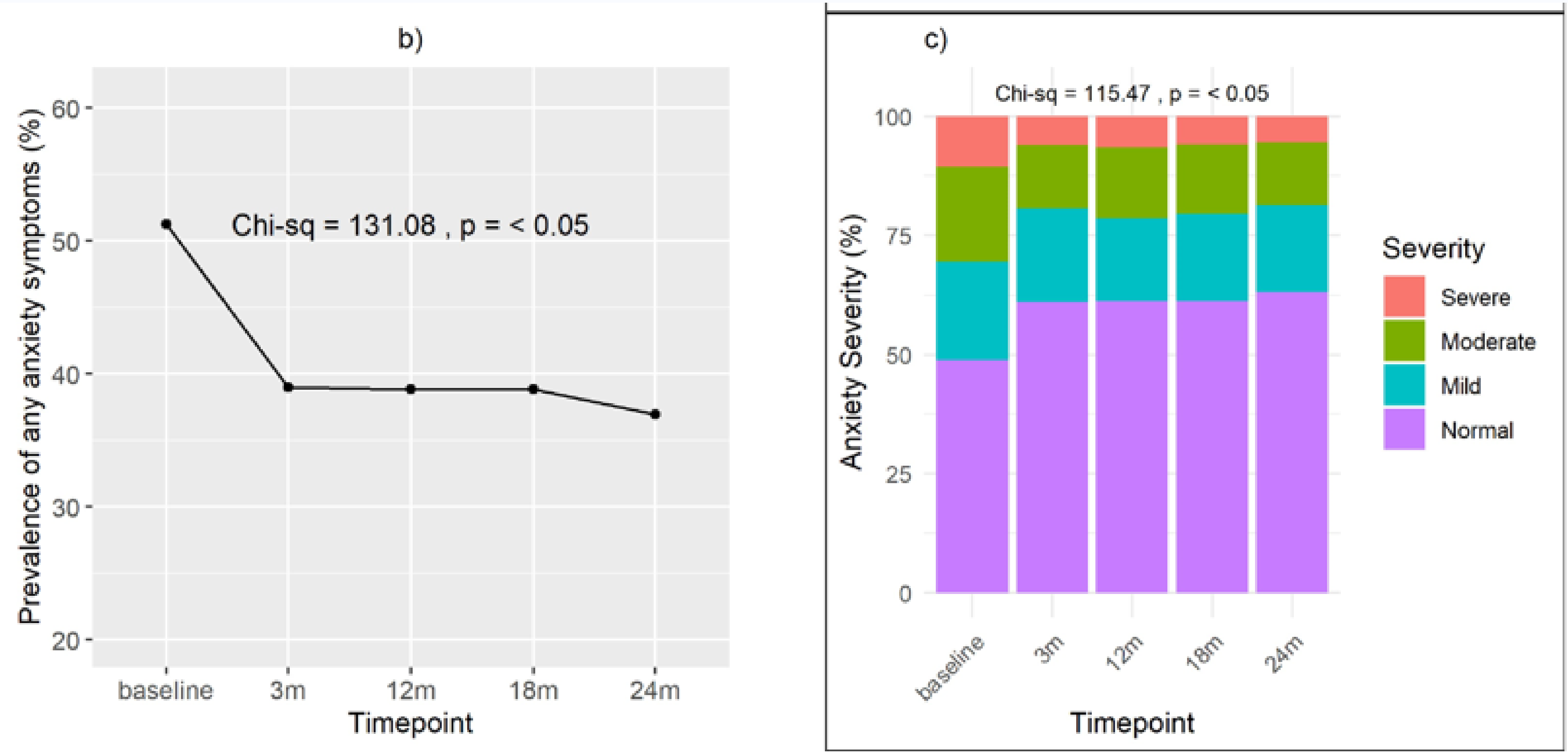
Understanding the impact of cancer diagnosis and treatment on everyday life

Depression (all groups)





Anxiety (all groups)



Aims: Public Stakeholder groups

- To discuss psychological needs
- To identify components and content of the online resource they would like to see
- To identify the outcomes that are important to them

Aims: HCP Stakeholder groups

- To identify the types of support online resources can provide that integrate well with clinical practice
- To identify components and content of the online resource they think are important

Patients / Carers: need for online support

Understanding	'I don't think the doctors and the nurse specialist don't explain that. They just use the term and it's kind of because it's a familiar term to them. And they use it without understanding what the implications are the to person. It goes back to the psychology of it all, I had to ask, "What does it mean"?' (NG1 P3)
Identification	'I think people don't always realise how far down the rabbit hole they are. I know I went to the doctor when I was on watch-and-wait, so I hadn't even had any treatment, and he looked up to me and said, "We thought you might be depressed," and it just didn't occur to me that was what was the matter with me.' (NG2 P4)
Connection	'I think from personal experience, it was not really being able to connect with anyone that understood. Like family, friends were an amazing support obviously, but it's trying to feel that you could find someone. Because obviously, there's a lot of people out there.' (NG1 P5)
Coping	'I would want it to be specifically to do with my psychology. The psychology of how I am coping with this and what I would need to do to change that, as opposed to it being another resource to go to as someone who'd been given a cancer diagnosis, because there are plenty out there.' (NG1 P3)
Reassurance	'what I would want from a website would be reassurance that there is hope and also, as I went through the process that, actually, it is right that what's happening. So, you know you'll get through it.' (NG1 P2)
Confidence	'[A resource should be] supportive, and then you can think: "Actually, what do they say about strategies?" But I could use it as a resource for me. You can take control of it. For me, it is all about control and getting some control back.' (NG1 P2)

Patient/carers: Explanation of priority

Supportive strategies (isolation)	‘I go on a caravan holiday every year with lots of friends and I sat in my caravan separate from them one evening and they were all laughing away and, “Ha, ha, ha!”, as they would be, all enjoying themselves. It was just like the window was a picture frame of a happy scene that I used to be part of, but I was still inside the caravan’ (NG2 P3)
What to expect (sex)	‘With me, I had the operation, you’ve got a bag, you have to deal with incontinence. I had these nappies and all that crap and therefore it puts you off sex, number one, if I’m being honest. You’re in a dark corner. In my case, I’ve got a young wife and I’ve got a son, and suddenly I’m in a dark corner and I’ve got to make sure I don’t wet myself’ (NG1 P1)
Fear (recurrence)	‘it still follows me around a little bit. So sometimes if you have similar symptoms, your mind goes to a bad place and I know last year, I had glandular fever, which sometimes lymphoma gets mistaken for, but I was thinking: “Gosh, it really resembles a little bit about how I felt at the time. I hope it’s nothing kind of worse”.’(NG2 P2)
Healthy Lifestyle	‘my experience is a lot of people are very afraid to exercise and so they stay at home, and they get more depressed because they feel lousy and then they get more depressed, but they can’t do anything and then they get weaker, so it’s like this vicious circle forms.’(NG1 P2)

HCPs: supported self-management

HCPs:

- currently refer people to information sites and Apps, e.g. Macmillan, Sleepio
- want a trusted, centralised tool to use with the individual
- want Can-Empower to help deliver supported self-management, e.g. something they can follow up with the individual

‘a lot of people don’t feel confident to choose an app themselves, so if you direct them to an app they feel much more confident using it. And then I think also if they can have some contact with a clinician about how they are using it, again for some people, I think that increases their confidence that they’re doing it right, as it were.’ (HCP5)

‘I do quite a lot around supported self management and follow up pathways for patients who have completed treatment, but it’s having that kind of contact afterwards that maybe it’s not just referring to a website, but you know those points where people can go back and say, “How did you get on?”, or really using it as a tool, not just to signpost to.’ (HCP6)

HCPs: Explanation of priority areas

Self-management strategies	‘a lot of people find that they, particularly at night, get in that sort of worry trap where everything starts spiraling out of control with their thoughts and feelings and just how to deal with that anxiety, and also the use of guided imagery as well. You know, if they don’t find mindfulness too much, just being able to tune in and listen to something that can help distract them.’ (HCP2)
Normalising	‘a lot of people come in and and say to me when they finish their treatment particularly that they feel like they should be better and they are not. And the feeling with that, that’s when they start to almost what they call slide off the scale. So, they start to feel depressed and anxious, because they’ve been on the hamster wheel of treatment. The first thing I say to them, ‘You’re not the first person to tell me this.’ And instantly you just see them completely relax.’ (HCP1)
Safety	‘you need to call your GP. It’s no good being on a kind of website at this point. If that’s happening, you need to call your clinical nurse specialists. You need to take the patient to hospital. So, I think if you’re going to have a website that’s about mental health, you have to acknowledge that some people might come to it in a really difficult place where the website is not what they need.’ (HCP5)

Think alouds: Participant characteristics

Participants: n=25

Participant type: Person with cancer n=19; Professional n =5; Carer n=7

Cancer type: Breast n= 7; Lung n=1; Ganglioneuroblastoma n=1; Follicular Lymphoma n=1; Malignant melanoma n=1; Ovarian n=1; Thyroid n =1; Brain n=1; Hodgkin's lymphoma n=1; Sarcoma n=4; Myeloma n=1; Prostate n=1; Testicular n=1.

Sex: Female = 20 Male = 5.

Ethnicity: White British: = 18, Any other white background = 3, Black British = 1 Black African = 1.

Age: (25-35 = 2) (35-44=3) (45-54=6) (55-64=4) (65-74=2) (75+=3)

Home testing: Participant characteristics

Participants: n= 17

Participant type: Person with cancer n= 15; Carer n= 2

Cancer type: Uterine n=6, Breast n=4, Melanoma n=2, Acute myeloid Leukaemia n=1, Cervical n=1, Non hodgkins lymphoma n=1,Oesophageal n=1, Prostate n=1.

Sex: Female = 15; Male = 2

Ethnicity: White British n= 16, Chinese n=1.

Age: (25-35 = 1) (35-44=1) (45-54=5) (55-64=4) (65-74=2) (75+=4)

Home testing feedback

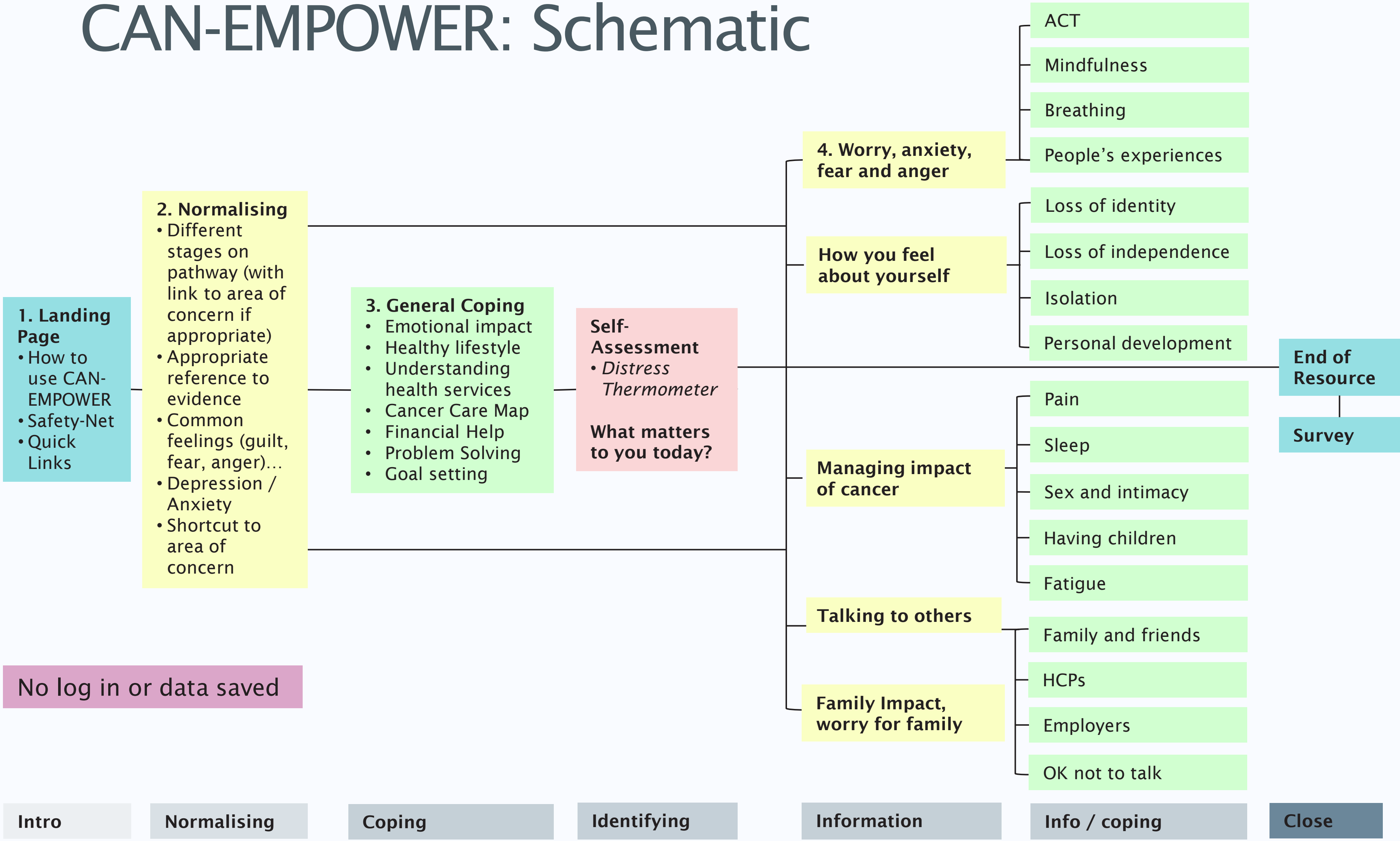
‘helped [me] to recognise and focus on strengths but also what to handover things rather than not losing something... [It] helped me to ground again.’ (PO27)

‘I wish I’d had this site when going through cancer…You’ve created a really valuable thing here…The website gives skills for life.’ (PO28)

‘[It] talks you through in a step-by-step guide way… [It] gives direction [as] there’s a big gap between diagnosis and what’s next and this helps fill the gap... [It] will be helpful all the way through the cancer journey.’ (PO31)

‘Healthy lifestyles are important for living well…shifting from passive to active and shifting control from medics to self... [It] helps build resilience...[It will] help people to cope better and have hope.’ (PO39)

CAN-EMPOWER: Schematic



1. Landing Page
- How to use CAN-EMPOWER
- Safety-Net
- Quick Links

2. Normalising
- Different stages on pathway (with link to area of concern if appropriate)
- Appropriate reference to evidence
- Common feelings (guilt, fear, anger)…
- Depression / Anxiety
- Shortcut to area of concern

3. General Coping
- Emotional impact
- Healthy lifestyle
- Understanding health services
- Cancer Care Map
- Financial Help
- Problem Solving
- Goal setting

Self-Assessment
- *Distress Thermometer*

What matters to you today?

4. Worry, anxiety, fear and anger
- ACT
- Mindfulness
- Breathing
- People's experiences

How you feel about yourself
- Loss of identity
- Loss of independence
- Isolation
- Personal development

Managing impact of cancer
- Pain
- Sleep
- Sex and intimacy
- Having children
- Fatigue

Talking to others

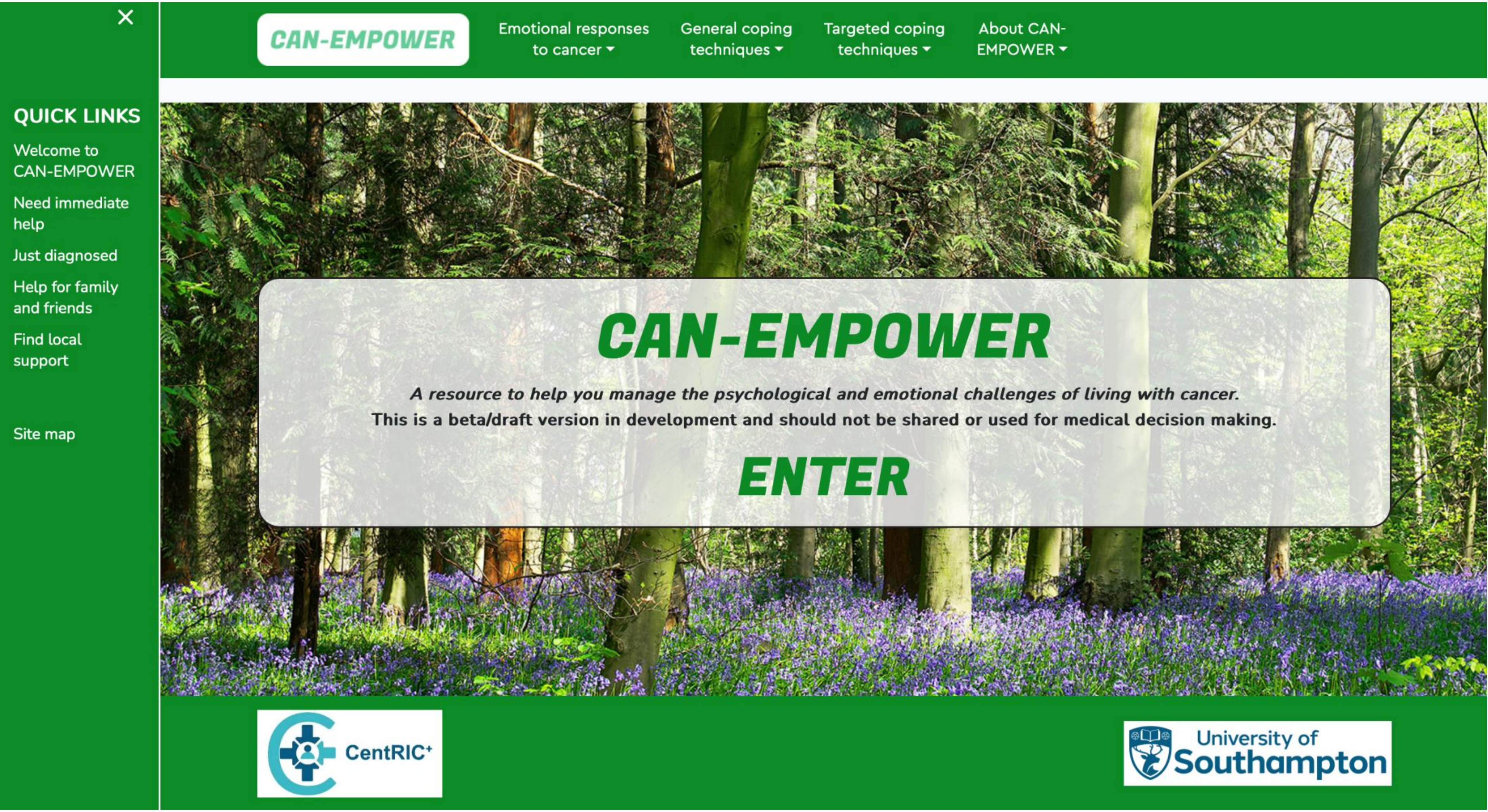
Family Impact, worry for family
- Family and friends
- HCPs
- Employers
- OK not to talk

End of Resource

Survey

No log in or data saved

Intro | **Normalising** | **Coping** | **Identifying** | **Information** | **Info / coping** | **Close**



CAN-EMPOWER

A resource to help you manage the psychological and emotional challenges of living with cancer.

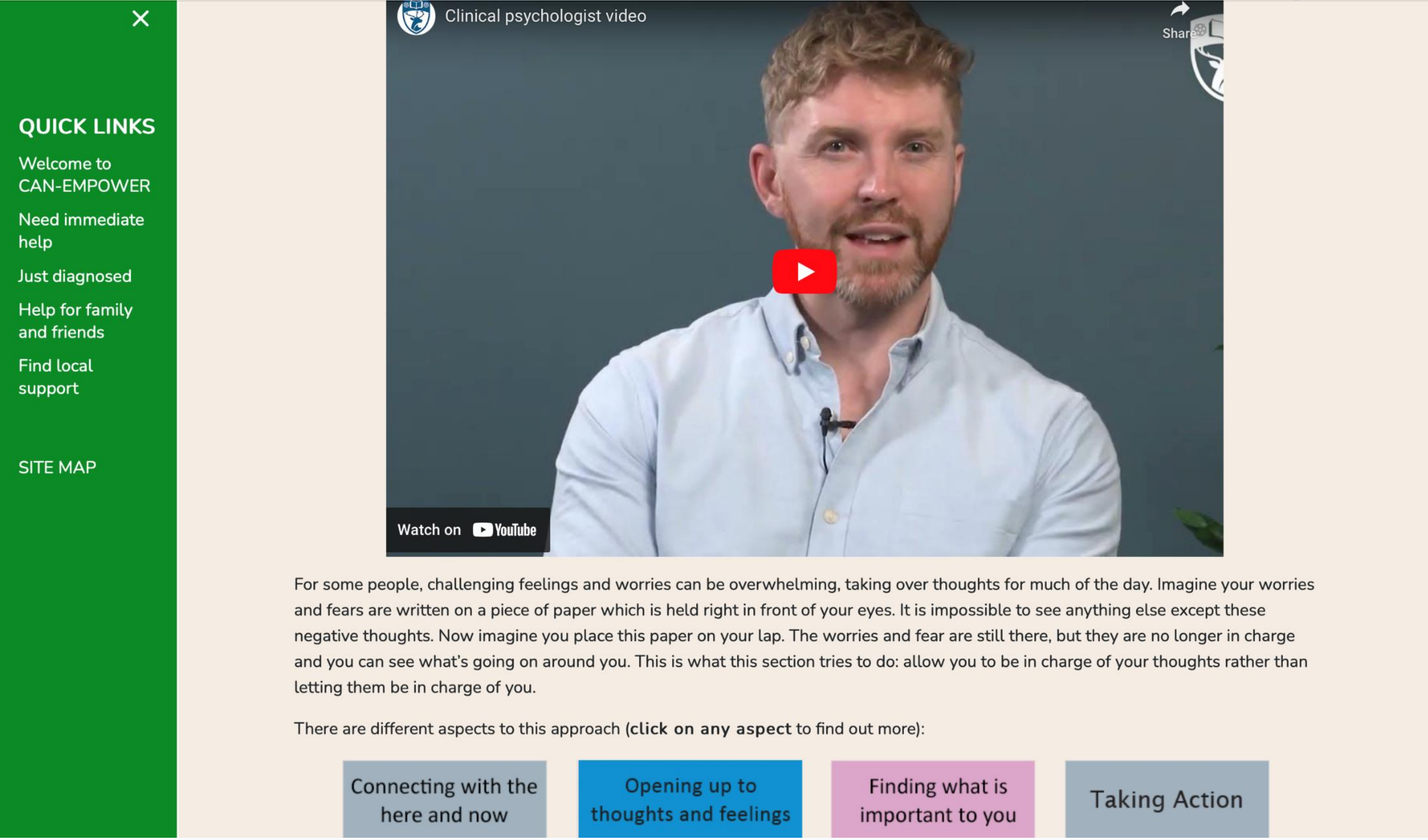
This is a beta/draft version in development and should not be shared or used for medical decision making.

Thoughts and Feelings

Joanna's story 2024

Living with cancer can be difficult. There are many thoughts and feelings you may experience from the moment you go for tests, through diagnosis and treatment, to when then your treatment ends. Thoughts are words or pictures we create in our minds, which may be about the future or memories of past events. Feelings are our moods, emotions and the physical sensations that often accompany thoughts.

You may feel there is pressure on you to be "brave", "strong", or to show the world you are determined to "fight". Or you may have been told it is important you "stay positive". Not everyone finds these words, or this pressure, helpful. Tricky, painful feelings such as sadness, worry or anxiety are felt by many people as they experience cancer. They are a completely understandable reaction to a threatening situation. These feelings can come and go. For some people, these feelings can last a long time, even if it has been years since treatment has ended.



For some people, challenging feelings and worries can be overwhelming, taking over thoughts for much of the day. Imagine your worries and fears are written on a piece of paper which is held right in front of your eyes. It is impossible to see anything else except these negative thoughts. Now imagine you place this paper on your lap. The worries and fear are still there, but they are no longer in charge and you can see what's going on around you. This is what this section tries to do: allow you to be in charge of your thoughts rather than letting them be in charge of you.

There are different aspects to this approach (**click on any aspect** to find out more):

QUICK LINKS

- Welcome to CAN-EMPOWER
- Need immediate help
- Just diagnosed
- Help for family and friends
- Find local support

SITE MAP

Goal Setting

Many people with cancer find setting goals and planning ahead helpful in coping with emotional challenges. Setting goals can help you feel more confident to live with problems relating to the cancer.

If you have already completed a healthy lifestyle plan, you may wish to look at it when thinking about your goals.

The following things may help you set your goals:

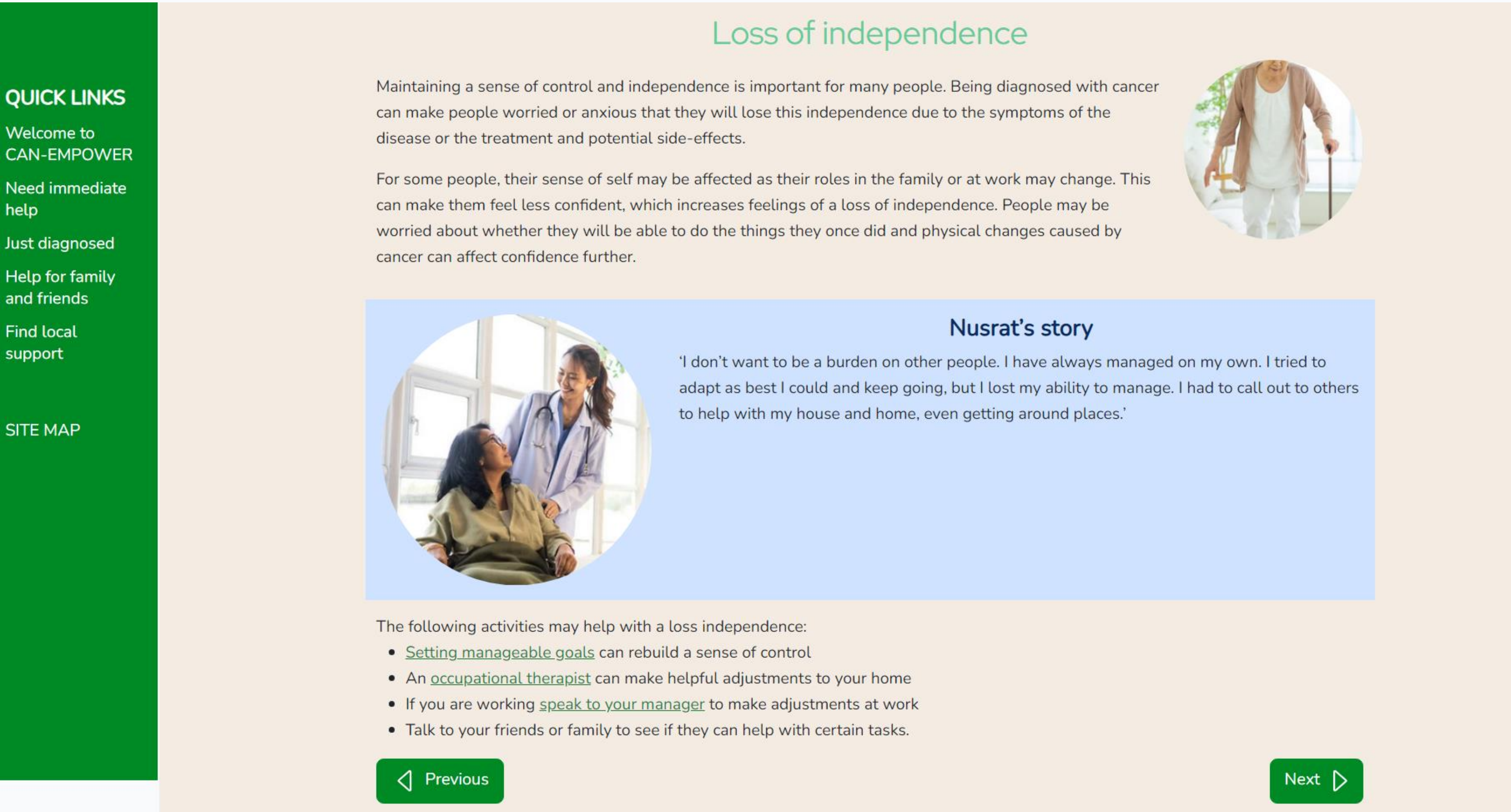
- Write down your goals. This can help you make a firm plan and turn your thoughts into actions.
- Focus on smaller, short-term goals. You are more likely to stick to your plan if you follow these.
- See your progress when you set short term goals and celebrate when you meet them. This can help you gain confidence to achieve those goals.

Defining your Goals

The first part of goal setting it to define what it is you want to fix. Take time out to write what aspects of living with cancer are causing you emotional or psychological problems.

1. What are the problems?
2. What impact is it having on you?
3. What would you like to fix?

Having written down what it is you want to fix, you can write a SMART objective for each problem. Click on each letter to find out more. If it is useful, you can click here to download a print version of these questions and SMART objectives guide.



QUICK LINKS

Welcome to CAN-EMPOWER

Need immediate help

Just diagnosed

Help for family and friends

Find local support

SITE MAP

Loss of independence

Maintaining a sense of control and independence is important for many people. Being diagnosed with cancer can make people worried or anxious that they will lose this independence due to the symptoms of the disease or the treatment and potential side-effects.

For some people, their sense of self may be affected as their roles in the family or at work may change. This can make them feel less confident, which increases feelings of a loss of independence. People may be worried about whether they will be able to do the things they once did and physical changes caused by cancer can affect confidence further.

Nusrat's story

'I don't want to be a burden on other people. I have always managed on my own. I tried to adapt as best I could and keep going, but I lost my ability to manage. I had to call out to others to help with my house and home, even getting around places.'

The following activities may help with a loss independence:

- Setting manageable goals can rebuild a sense of control
- An occupational therapist can make helpful adjustments to your home
- If you are working speak to your manager to make adjustments at work
- Talk to your friends or family to see if they can help with certain tasks.

Next Steps

- Aesthetics, accessibility and web-design
- Future sustainability
- Dissemination, communication, implementation
- Launching before Christmas

Practice integration

- A centralised resource, containing trusted information and links to further support
- Designed for people with less complex psychological need (aligned with Level 2 practice)
- Available 24 / 7 will no password, paywall or data sharing required
- Contains activities and exercises that can be completed under the supervision of HCPs
- Can be used at 'Cancer Care Review,' and then followed with the individual
- Aim is that over time, people will feel more confident to manage psychological and emotional difficulties.

Points for discussion

- What is the place of digital interventions in supporting your practice?
- How could you implement this in your practice?
  - How could we support professionals to implement?
- Pathways/opportunities for impact?
- What are the next steps?